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ABSTRACT

Questionnaires completed by 34 epilepsy clients of a long-term comprehensive and decentralized neurological center are analyzed, and professional staff time-statistics are considered in terms of staff member-client interaction time. Survey responses are outlined for the following aspects (sample findings in parentheses): the five most important things about the services which help meet the client's total needs (involvement with home and school, open communication with staff members); five most important things about the services which fail to meet the client's total needs (inadequate staff numbers, lack of communication with doctors); benefits of home treatment (more personal in nature, better relationship between staff number and child); benefits of center-based treatment (opportunities to meet other parents, advantages of group treatment); benefits of treatment at the preschool or school (better communication between the school and center staff); preferred setting; parent education; parent involvement, parent-staff relationship; and professional involvement. (CL)

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THE MOBILE DELIVERY OF A COMPREHENSIVE PROGRAM BY A MULTIDISCIPLINARY TEAM: STATISTICAL PAPER

CANT, Malcolm J.
September, 1978
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INTRODUCTION

The philosophy of the Vancouver Neurological Centre is unique in that the Centre endeavors to provide a long-term comprehensive and decentralized program for its clients; namely, that treatments are conducted in the home and at the school/pre-school where possible, instead of the centre proper.

MATERIALS AND METHODS

Of the 197 clients with epilepsy who have been with the Centre since 1974, 45 clients were randomly sampled to be the recipients of a survey questionnaire. There was a 75.5% return of the questionnaires; i.e. 34 from the original 45 that were mailed out. The questionnaires were constructed so that there was no way in which the client, respondent, could be identified by the investigator.

For the years 1975 through to a pro-rated 1978 year, the professional staff time-statistics were compiled so that an investigation of actual staff member-client interaction time could be pursued. The statistics were compiled for the epilepsy caseload, cerebral palsy caseload, Parkinson's caseload, and the total caseload in order that the total statistical picture could be presented; this being a more realistic overview of the value of a decentralized program.

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Table I THE STAFF MEMBER-CLIENT INTERACTION TIME FOR INDIVIDUAL, GROUP AND FAMILY CONFERENCE SESSIONS PER WORKING DAY

Social Work	Epilepsy	Cerebral Palsy	Parkinson's	Total
1975	3.15	2.03	0.03	5.48
1976	3.24	1.41	0.33	4.98
1977	3.39	1.74	0.36	5.49
1978	3.72	1.11	0.56	5.39

Occupational Therapy	Epilepsy	Cerebral Palsy	Parkinson's	Total
1975	1.05	2.30	-	3.35
1976	1.47	3.24	-	4.71
1977	2.40	3.58	-	4.98
1978	2.56	3.72	-	6.28

Speech Therapy	Epilepsy	Cerebral Palsy	Parkinson's	Total
1975	2.06	2.95	0.00	5.01
1976	0.70	3.85	0.03	4.58
1977	1.37	4.04	0.30	5.71
1978	1.25	3.58	0.34	5.17

Educational Consultant	Epilepsy	Cerebral Palsy	Parkinson's	Total
1975	1.11	2.95	-	2.26
1976	1.89	0.96	-	2.85
1977	3.21	1.29	-	4.50
1978	4.11	1.72	-	5.83

Physiotherapy	Epilepsy	Cerebral Palsy	Parkinson's	Total
1975	0.25	5.19	-	5.44
1976	0.20	4.77	-	4.97
1977	0.28	4.85	-	5.13
1978	0.26	6.09	-	6.35

The statistics that are contained in Table I represent the staff member-client interaction time on the basis of individual sessions, group sessions and family conferences inclusive.

The statistics do reflect the working days that are lost per year due to:

- annual vacations,
- statutory holidays (11 per year),
- professional advancement time, and,
- staff turnovers when there is less than the normal staff complement in a department.

The statistics do not reflect the working time that is lost per year due to:

- sick leave,
- open days,
- lectures for student groups,
- staff meeting time, and,
- telephone contacts.

It can be seen that, for a regular working day, the Social Worker spends 5.39 hours per day in 1978 in actual client contact, 3.72 hours being for clients with epilepsy.

, the Occupational Therapist spends 6.28 hours per day in 1978 in actual client contact, 2.56 hours being for clients with epilepsy.

, the Speech Therapist spends 5.17 hours per day in 1978 in actual client contact, 1.25 hours being for clients with epilepsy.

, the Educational Consultant spends 5.83 hours per day in 1978 in actual client contact, 4.11 hours being for clients with epilepsy.

, the Physiotherapist spends 6.35 hours per day in 1978 in actual client contact, 0.26 hours being for clients with epilepsy.

The results that were obtained from the survey questionnaire are as follows:

THE 5 MOST IMPORTANT THINGS ABOUT THE SERVICES GIVEN BY THE CENTRE, THAT HELP TO MEET THE TOTAL NEEDS OF THE CLIENT

(30)	Involvement with home and school	(88.2% of the responses)
(30)	Open communication with staff members	(88.2% of the responses)
(28)	Informed about client's progress	(82.4% of the responses)
(26)	Cost of treatment is based on income	(76.5% of the responses)
(24)	The variety of services	(60.6% of the responses)
(16)	Individual home treatments	(47.1% of the responses)
(6)	Personal relationship built up with staff members	(17.6% of the responses)
(2)	Can select the location for treatment	(5.9% of the responses)
(2)	No other Centre available in the city	(5.9% of the responses)
(0)	Staff members are like one of the family	(0% of the responses)
(0)	Others	(0% of the responses)

It can be seen that the five (5) most important factors about the services that are supplied, are:

- with 88.2% of the responses, the involvement with home and school,
- with 88.2% of the responses, the open communication with staff members,
- with 82.4% of the responses, being informed about the client's progress,
- with 76.5% of the responses, the cost of treatment based on income, and
- with 70.6% of the responses, the variety of services.

THE 5 MOST IMPORTANT THINGS ABOUT THE SERVICES GIVEN BY THE CENTRE, THAT FAIL TO MEET THE TOTAL NEEDS OF THE CLIENT

(28)	Not enough staff	(82.4% of the responses)
(18)	*Lack of communication with doctors	(52.9% of the responses)
(14)	Not enough treatment sessions	(41.2% of the responses)
(6)	Parents not informed of client's progress	(17.6% of the responses)
(4)	Lack of communication with parents	(11.8% of the responses)
(4)	More pressure should be put on fathers to help	(11.8% of the responses)
(2)	Not enough practical advice given	(5.9% of the responses)
(0)	Too demanding of parents	(0% of the responses)
(0)	Invasion of family privacy	(0% of the responses)

It can be seen that the five (5) most important factors that the respondents feel that fail to meet the total needs of the client are:

- with 82.4% of the responses, not enough staff,
- with 52.9% of the responses, lack of communication with doctors,
- with 41.2% of the responses, not enough treatment sessions,
- with 17.6% of the responses, parents not informed of client's progress,
- with 11.8% of the responses, lack of communication with parents, and, more pressure should be put on the fathers to help.

* All physicians receive the written reports of staff members who are involved with their particular referred patients so this may be a case of physicians not reading their mail!

WHAT ARE THE BENEFITS OF TREATMENT AT THE HOME FOR YOUR CHILD AND YOURSELF?

(24)	Program is more personal in nature	(70.6% of the responses)
(24)	Program builds a better relationship between staff member and child	(70.6% of the responses)
(16)	Child co-operates much better at home	(41.1% of the responses)
(16)	Do not have transportation or parents unable to drive	(41.1% of the responses)
(14)	More carryover by the parents of what staff member demonstrates	(41.2% of the responses)
(2)	Program adapted to facilities at home	(5.8% of the responses)
(0)	It is not different to treatment at the Centre	(0% of the responses)

The two main benefits of home based treatments are:

- with 70.6% of the responses, that the program is more personal in nature, and, that the program builds a better relationship between staff member and child.

WHAT ARE THE BENEFITS OF TREATMENTS AT THE CENTRE FOR YOUR CHILD AND YOURSELF?

(16)	The opportunity to meet other parents, see other children	(47.1% of the responses)
(16)	A group treatment better suits the needs of the child	(47.1% of the responses)
(8)	Have no babysitting or transportation problems	(23.5% of the responses)
(4)	It is more professional to go to the Centre	(11.8% of the responses)
(2)	The opportunity to get out of the house	(5.9% of the responses)

The two main benefits of the Centre based treatments are:

- with 47.1% of the responses, the opportunity to meet other parents and to see other children, and, a group treatment better suits the needs of the child.

It is interesting to note that 47.1% of the respondents have transportation problems while only 23.5% of the respondents have no babysitting or transportation problems, and, that there were 96 responses to the 'benefits of treatment at home' question as opposed to 46 responses to the 'benefits of treatment at the centre' question.

WHAT ARE THE BENEFITS OF TREATMENTS AT THE SCHOOL/PRE-SCHOOL FOR YOUR CHILD AND YOURSELF?

(26)	Teacher will know what staff member is doing with the child	(76.5% of the responses)
(26)	There is better communication between the school and Centre staff	(76.5% of the responses)
(26)	Potential problems in class can be avoided	(76.5% of the responses)
(20)	Closer personal relationship develops between teacher, staff member and parent	(58.8% of the responses)
(16)	Parents are better informed of child's progress in school	(47.1% of the responses)
(14)	Child misses less school work than if he/she has to go in to the Centre	(41.2% of the responses)
(4)	Teachers learn more about the child's special problems	(22.8% of the responses)
(0)	It is no different from treatment at the Centre	(0% of the responses)

The three most popularly checked benefits of school/pre-school based treatments are:

- with 76.5% of the responses, that the teacher will know what the staff member is doing with the child, that there is better communication between the school and the Centre staff, and, that potential problems in class can be avoided.

AT WHAT LOCATION DO YOU FEEL THAT YOUR CHILD BENEFITS MOST FROM HIS/HER TREATMENTS WITH STAFF MEMBERS?

(20)	Home	(58.8% of the responses)
(8)	School/Pre-School	(23.5% of the responses)
(4)	Location isn't a factor	(11.8% of the responses)
(2)	Centre	(5.9% of the responses)

It can be seen that, with 58.8% of the responses, that the respondents felt that their child benefits most from home treatments with the staff members. This fits in with the 88.2% response rate for "involvement with home and school" as the most important factor about the services that are given by the Centre. (Question 1 on the questionnaire).

HAVE YOU LEARNED MORE ABOUT YOUR CHILD's EPILEPSY THROUGH . . .?

(16)	Home treatments	(47.1% of the responses)
(12)	Film and lecture	(35.3% of the responses)
(3)	Doctor	(8.8% of the responses)
(2)	Centre Treatment	(5.9% of the responses)
(1)	School/Pre-school treatments	(2.9% of the responses)

47.1% of the respondents indicated that they had learned more about their child's epilepsy through home treatments, while 35.3% felt that they learned more via the film and lecture presentation. The Neurologist in charge of the Epilepsy caseload of the Centre makes a public film and lecture presentation three times per year at the Centre. All parents, clients and interested members of the public are invited to attend these presentations.

HAVE YOU LEARNED MORE ABOUT YOUR CHILD'S DEVELOPMENTAL PROGRESS (0-5 years) THROUGH . . .?

(16)	Home treatments	(47.1% of the responses)
(6)	Pre-school treatments	(17.6% of the responses)
(0)	Centre treatments	(0% of the responses)
(0)	Other locations	(0% of the responses)

It must be pointed out that referrals that come in to the Centre are not all at the early age at which we would rather commence our work with the child. As a result of this, not all the respondents could check a response to this question. 47.1% of the respondents felt that they learned more about their child's developmental progress through the home treatments.

HAVE YOU LEARNED MORE ABOUT YOUR CHILD'S SCHOOL FUNCTIONING THROUGH . . .?

(22)	School/Pre-School treatments	(64.7% of the responses)
(4)	Home treatments	(11.8% of the responses)
(4)	Centre treatments	(11.8% of the responses)
(0)	Other	(0% of the responses)

An overwhelming 64.7% of the respondents were of the opinion that they learned more about their child's school functioning through school/pre-school treatments. I had a faint suspicion that this would be so!

DO YOU FEEL THAT YOU CAN CONTRIBUTE MORE TO YOUR CHILD'S TREATMENT, AND THUS PROGRESS, FROM STAFF TREATMENTS THAT ARE GIVEN AS . . .?

(24)	Home treatments	(20.6% of the responses)
(8)	School/Pre-school treatments	(23.5% of the responses)
(2)	Centre Treatments	(5.9% of the responses)
(0)	Other	(0% of the responses)

Home treatments were felt to be more beneficial in the parental contribution toward child treatment and progress by 70.6% of the respondents. Only 5.9% of the respondents felt that the Centre treatments were more beneficial in this regard.

DOES A CLOSER BOND DEVELOP BETWEEN THE STAFF MEMBER AND CHILD AS A RESULT OF . . . ?

(26)	Home treatments	(76.5% of the responses)
(6)	School/Pre-school treatments	(17.6% of the responses)
(2)	Centre treatments	(5.9% of the responses)
(0)	Other	(0% of the responses)

It was felt by 76.5% of the respondents that a closer bond developed between the staff member and child as a result of home treatments. This question was put in to assess the validity of the responses to the question of "the benefits of treatments at the home for your child and yourself". To this question 70.6% of the respondents felt that, "the program was more personal in nature", and the "program builds a better relationship between staff member and child".

WHAT PROFESSIONALS SHOULD BE INCLUDED IN A TEAM WHICH IS TO SERVE THE TOTAL NEEDS OF THE CHILD WITH EPILEPSY AND HIS/HER FAMILY?

(30)	Neurologist	(88.2% of the responses)
(28)	Family Physician	(82.4% of the responses)
(28)	Educational Psychologist	(82.4% of the responses)
(26)	Special Education Consultant	(76.5% of the responses)
(25)	Occupational Therapist	(73.5% of the responses)
(20)	Social Work	(58.8% of the responses)
(20)	Speech Therapist	(58.8% of the responses)
(17)	Play Therapist	(50.0% of the responses)
(12)	Recreation Therapist	(35.3% of the responses)
(10)	Child and Adolescent Psychiatrist	(29.4% of the responses)
(9)	Vocational Psychologist	(26.5% of the responses)
(8)	Music Therapist	(23.5% of the responses)
(4)	Pediatrician	(11.8% of the responses)
(3)	Nurse	(8.8% of the responses)
(2)	Clinical Psychologist	(5.9% of the responses)
(1)	Physiotherapist	(2.9% of the responses)
(0)	Other	(0% of the responses)

The medical professionals lead the list with 88.2% and 82.4% of the responses for neurologists and family physicians respectively.

The educational and developmental professionals follow with 82.4%, 76.5% and 73.5% of the responses for educational psychologists, special education consultant and occupational therapist respectively.

The next three response ordered choices have their involvement more in the home and social situation (as well as the school to a degree!). They are the social worker, speech therapist and play therapist with 58.8%, 58.8% and 50.0% of the response respectively. The latter response was a very surprising result for the investigator and I can offer no concrete reasons for its position of status. However, a guess would be, that it is related to the problem of a lack of neighbourhood and school friendships on the part of some epileptic children.

DISCUSSION

One of the most frequently used arguments against the implementation of a decentralized or mobile program of any type is the lack of actual client interaction time. However, it can be seen that a well structured decentralized program can have a very acceptable number of hours per day of client interaction for all the departments within a comprehensive centre.

Admittedly, there has not been an investigation of the comparison between the cost in dollars and cents for the operation of a centralized service and a decentralized service. A comparison such as this, should also look at the long term result of this investment of public purse monies rather than an on-the-spot one crack investigation.

There has been definite evidence presented that the clients of the Centre are justly satisfied with the program that meets their needs in the home, the school and the community, and, with the composition of the team that is utilized to serve their needs.

I will conclude this brief presentation by reiterating the remarks that Dr. Feindel made during his Guest Lecture at the Opening Ceremony of this Epilepsy International Symposium . . . "there is a need for comprehensive programs for persons with epilepsy".